Young people's experience of individual Cognitive Remediation Therapy (CRT) in an inpatient eating disorder service: a qualitative study

Abstract

Introduction and Purpose Current literature shows promising results regarding the efficacy of Cognitive Remediation Therapy for Anorexia Nervosa (AN), however there is a paucity of studies considering the use of CRT in Young People (YP). The aim of this study was to examine YP's experiences of individual CRT in an inpatient eating disorder unit.

Method Seventy letters following a cycle of eight individual CRT sessions were analyzed using thematic analysis, adopting an inductive approach. Inter-rater reliability of findings was ensured.

Results The following six-higher order themes, each with lower order themes, were identified: Engaging aspects of CRT; Identifying thinking skills; Relevance to real life situations; Encountering personal challenges; Making sense of the rational of CRT; Suggestions for further improvements. YP reported enjoying CRT and described increased learning about their thinking styles and their skills from the activities undertaken during therapy. Some participants were able to apply learning outside of therapy and, less frequently to difficulties related to the illness. A few struggled to understand the goals of CRT, asking for more information about the purpose.

Conclusions Feedback from patients suggests CRT is a useful intervention for YP with AN, which could facilitate their engagement in the treatment, while tackling neuropsychological processes underlying psychological symptoms of AN. Exploring participants' experience of CRT has highlighted specific elements of the intervention perceived as beneficial by YP, and areas where adaption could be made. This

will allow clinicians to further develop the intervention from a service users' perspective, tailoring the sessions to their needs.

Keywords

Anorexia nervosa, cognitive remediation therapy, young people, qualitative study, service users' experience

Introduction

Anorexia Nervosa (AN) is a life-threatening Eating Disorder (ED) with a lifetime prevalence of up to 3.6 – 4 %, according to DSM-5 criteria [1, 2]. It is characterised by an intense drive for thinness and determined weight loss; distorted cognitions regarding weight and shape; and intense preoccupation with weight, shape and food [3]. Its etiology is complex and multi-factorial [4], and there is still an insufficient evidence base for treatment efficacy in young people (YP) suffering from AN [5].

There is a growing body of studies that examine and delineate the neuropsychological profile of AN adults [6, 7, 8]. Research into the neuropsychology of AN has consistently revealed inefficiencies in the cognitive domains of central coherence, namely the ability to see the 'bigger picture' [for a review 6, 7, 9], set-shifting or cognitive flexibility, [8, 10] and visuo-spatial processing [11]. However, only a limited number of studies have focused on exploring cognitive performances in YP [for reviews 9, 12].

Cognitive Remediation Therapy (CRT) is a promising novel treatment for AN [13, 14, 15, 16] which could facilitate engagement in treatment, while tackling neuropsychological processes underlying psychological symptoms of AN. Gathering participants' experience of CRT could help to highlight key elements of this intervention and what specific factors are perceived as more helpful by patients [15, 17, 18].

In the adult population, qualitative feedback indicates that patients' are satisfied with CRT, received individually or in a group setting, and found the treatment helpful in reducing perfectionist and rigid tendencies and processing information more holistically and flexibly [17, 19, 20]. Patients appreciated that CRT involved thought processes versus content; and emotions and feelings were not directly explored [16, 20]. Many expressed how they were able to translate skills and knowledge learnt during the therapy into their lives outside of the clinical settings [20, 21]. They suggested changes to the intervention such as varying levels of difficulty and more guidance at implementing skills [17]. They also appreciated that the intervention did not focus on eating and food. Rance et al. [22] conducted a qualitative study of 12 women who were recovered or in recovery for AN, expressed a high degree of dissatisfaction with the standard treatment being overly focused and driven by food and weight. The lack of focus on eating and food has been seen as crucial to eliciting the service users' engagement in therapy, and has been confirmed by other studies [13, 23, 24].

More effective and engaging treatments for AN in children and adolescents are required, and may impact positively on prognosis. The voice and experience of YP represent an important element to guide development of this, however, there is currently limited evidence of how CRT is perceived by YP.

The present study aimed to explore the experience of YP suffering from AN in receiving individual CRT in a child and adolescent ED inpatient unit.

Methods

Setting and participants

The unit offers a multi-disciplinary treatment including individual therapy, family therapy and group therapy consisting of psychoeducational groups on nutrition, eating disorders and relapse prevention. In 2014 CRT was included as part of the existing treatment programme. Every participant in the hospital received therapeutic interventions in addition to CRT. This is an evaluation of CRT conducted since 2014

to present. All patients sequentially admitted to a specialist unit for ED received CRT under their and their families' informed consent. Participants were receiving adequate nutrition to meet their needs (either a weight gaining or maintenance prescription according to weight for height percentage) prior to starting the CRT sessions.

A total of 103 participants engaged in CRT in the treatment programme. All participants were female, aged 11 to 17 years (M = 14.8, SD = 1.6). All had a diagnosis of AN based on DSM-5 criteria. Thirty-three participants (32.1%) were unable to complete the study: 4.9 % (N= 5) were discharged or transferred prior to completing the course of CRT; 27.2% (N=28) did not write feedback letters saying that they did not know what to write or felt self- conscious about expressing their thoughts and feelings about the therapy. A total of 70 (68%) participants are included in the present qualitative study.

Procedure

The Intervention. The individual CRT began at the start of admission. It involved tasks, exercises, games and puzzles, which aimed to help YP to improve their flexibility in thinking styles and their ability to look at the 'big picture' as opposed to focusing on details. Trained assistant psychologists delivered the therapy. This work was supervised weekly by a clinical psychologist. The intervention consisted twice weekly, eight 45 minutes sessions. The total elapsed time between the pre-CRT assessment and the post-CRT assessment averaged four weeks. The structure of the CRT was based on the CRT Manual developed by Tchanturia et al. [25]. Some tasks utilised were added from the CRT Resource pack by Lindvall, et al. [26] specifically adapted for adolescents with ED. The content of sessions varied depending on age and need of the participant as delineated by the pre-CRT assessment, as well as from routine clinical observation.

Generally in each session therapists explored one or more cognitive domains such as: cognitive flexibility, cognitive inhibition, central coherence; visuo-spatial processing, memory and planning.

Games, puzzles and riddles were used to explore these domains. The games were developmentally appropriate and suitably challenging for the age group. These included pen and paper games (e.g. Embedded words and Geometric figures), board games (e.g. Rush Hour®; Serpentiles®, Tower of Hanoi®) and media (e.g. The Spinning Dancer®). For further information about games and media see [26]. Furthermore, a homework task related to the YP everyday routines (e.g. changing morning routine and organising schoolwork) was assigned and reviewed in the following session (for further information about the CRT protocol see [27].

Data collection. Following Whitney et al. [17] methodology, at the end of CRT, therapists provided YP with a letter, which summarised the content of the therapy. YP were asked to provide a feedback letter with a summary of their views. YP were given the timeframe of one week, and a further meeting was scheduled for the exchange of letters between therapists and YP. YP were asked to write about their thoughts and feelings during the sessions; what they found helpful and challenging and any suggestions for further improvement of the therapy.

Data Analysis

Thematic Analysis. Letters written at the end of treatment were analysed using thematic analysis, a widely used qualitative analytic method. The method allows researchers to identify and analyse recurrent themes across a set rich of data, but also to interpret several aspects of the research topic. It can be used as an exploratory method for investigating an under-researched area. In this instance, adopting an inductive approach, driven by the data, allows the researcher to gain a thematic description of the entire data set, and also to highlight the predominant themes. The analytic process involves a progression from description to interpretation. Initially the semantic level of the data is analysed: the researcher familiarise themselves with the data; generates initial codes; search for themes and the data are then organised and

summarised to show relevant themes. In the subsequent phase, a deeper meaning and implications of the themes is sought at a latent level by defining the themes and producing the final report [28].

An inductive approach, where the themes were generated from the data rather than a predisposed theory, was adopted. Through its theoretical freedom, thematic analysis provides a flexible and accessible research tool, which can generate a rich and complex account of qualitative data [28]. Given the varying length and detail of the letters provided by YP, and the exploratory nature of this study, thematic analysis based within an essentialist paradigm was deemed the most suitable methodological approach.

All letters were collected by the assistant psychologists delivering CRT, anonymised and given an identifiable code. They were then examined by the first and third author separately, to ensure inter-rater reliability of findings. Initially, letters were read repeatedly by both authors so that they could familiarize with the general content. Key words were identified for each letter and listed separately. Key words were then organised in higher categories. The first and third author met to discuss and analyse the higher categories. Both authors felt that data saturation had been reached and no new themes were emerging from the data.

In order to reinforce the reliability of the findings and provide a less biased interpretation the third author examined the letters without knowledge of the YP and their engagement, having only a theoretical knowledge of the structure and process of therapy. The first author supervised the assistant psychologists delivering the CRT to YP.

Higher order themes are presented throughout the results section with supporting quotes; pseudonyms are used to maintain YP anonymity.

Results

Sample Characteristics

The final sample consisted of seventy participants; the mean age was 14.8 (SD 1.6, range 11-17). The Weight for Height (WfH) percentage was measured at the beginning of the CRT course (Mean 78.1; SD

7.8, range 63.9-110.1). Sixty-two (88.5%) were White British; eight (11.4%) Asian and two (2.8%) White-Asian. They were all enrolled in Secondary school.

Higher and lower-order themes

The first and third author met to agree consensus on themes, this was discussed further in supervision with principal investigators (KT and AE); following this eight categories were identified. These were merged into six categories, for which sub-categories and relevant themes were also determined. The six higher-order themes are each discussed below with reference to lower-order themes. Figures and percentages of YP mentioning both higher order categories and sub-themes are reported (Table 1). Supporting quotations and in text references are presented using pseudonyms to ensure anonymity.

TABLE 1- INSERT HERE -

Engaging aspects of CRT

Thirty-six (51%) YP reported enjoying CRT. Twenty-two (32%) YP said they liked the exercises, especially the Illusions task and Rush Hour task, which seemed the most popular. They described how the strategies used in the tasks could be helpful at different times in their lives. They found the Illusion task meaningful as it allowed an understanding of changing perspective, which they did not expect. In relation to the Rush Hour, the player is a policeman who needs to get the red car off the road during a traffic jam, there are four levels of difficulty. From a stuck position they need to find strategies to move easily around the grid. YP often compared the stuck red car to themselves 'stuck' in the hospital because of the ED. Others (N=7; 10%) said they liked learning more about how their mind worked and about their thinking styles. This appeared a new experience for many. Few (N=4; 5.7%) YP described CRT as a useful distraction. For example Lucy said: '*I enjoyed the games and the creative exercise. It gave me a bit*

of space from everything else'. Two (2.8%) YP found the homework interesting; one (1.4%) commented on the need to have frequent sessions as this gave continuity to the work.

Identifying thinking skills

Thirty-four (48%) identified what they had learned during CRT. The majority (N=24; 34.2%) stated they learned about thinking styles and problem solving strategies. They found it helpful practicing cognitive inhibition skills and using these skills to block out unhelpful thoughts during meal times or other stressful situations. Catherine said: *'I think the most helpful things was working on my ability to block things out as I have been able to put that into practical use, such as blocking out unhelpful things at the table and focusing on one thing'.* Few (N=5; 7.1%) YP reported that CRT helped them to develop awareness of their personal struggles and their skills (e.g. planning). Camilla described that while she was playing Rush Hour she understood what was stopping her from moving forward with the treatment programme. Others (N=5; 7.1%) found it helped them find a balance between approaches focused on the big picture *vs.* details. Megan said: *'Looking at the big picture is also relevant to real life, especially in stressful situations where it is important to prioritise, such GCSE'.*

Relevance to real life situations

YP described what they learnt in CRT and when they were able to use this learning in daily life. Seven per cent of YP commented that they applied CRT to their routine, describing situations that allowed them to apply the learning from therapy to life, for example within their school routine and work planning. One YP, Naomi, appreciated the focus on the therapy and not on ED. She felt that this would be helpful from a longer term perspective, *'I would like to thank you for your time and support on coping with problems and issues in everyday life outside of an ED, which may apply when I am discharged and face real life again'.*

Encountering personal challenges

Some YP (N=14; 20%) found CRT challenging, when they tried to use alternative thinking styles (N=5; 7.1%), or engaged with tasks like Stroop, Illusions, and inhibition tasks (N=4; 5.7%). Despite difficulties tasks were described as stimulating. Some YP (N=5; 7.1%) struggled with dealing with changes in their routine. In this respect, Ellen said: '*I discovered that I do not like changes, but over the course of my CRT meetings I attempted to change small things. Most of them felt weird, but some changes were good and did not make a difference to my daily routine'.*

Making sense of the rational of the CRT

Fifteen (21.4 %) YP struggled to identify goals of CRT and two struggled to see any benefits. They were direct and succinct in feedback, asking 'What is the point? '. Others, like Magda, explained frustration in not being able to make use of CRT in their recovery. '*I have to admit that I do not feel that the sessions have contributed to my recovery or helped me in relation to any of my struggles, but they have been fun at times…I have tried really hard to engage in the sessions. However, as much as I looked into the meaning of it all, I can't see any response that leads to a new discovery in relation to my illness and methods of thinking*'. Where YP struggled with CRT they also seems to struggle to engage in other aspects of the treatment programme. Furthermore those that struggled to understand the aims of CRT also struggled to perceive any benefits and relate what they practiced in CRT to their symptomatology.

Suggestions for further improvements

Twenty (28.5%) YP included in letters their thoughts and suggestions for improvements of the therapy. Seven (10%) commented on length, frequency and setting of the sessions, for example *'I think you should carry on doing it regularly with everyone not just four weeks for it have more of an impact'.* A few (N=5;

7.1%) YP requested more games and challenging exercises and practising them in a group format. In respect to this Gina said: '*I think that CRT could be improved by having more and longer sessions because they are so much fun. I also think it would be interesting to do some group CRT as well as individual'*. Three (4.2%) YP suggested it could be useful to have more explanatory information regarding content of sessions. Similarly, few (N=3; 4.2%) YP advised the use of homework books so it could be discussed and perhaps be more useful. One (1.4%) made a comment that the assessment questions were similar and difficult to answer; and another YP encouraged to use a personalised approach.

Discussion and Conclusion

The majority of YP (68%) seemed to have appreciated the engaging nature of CRT. This is a key element when working with children and adolescents suffering from AN, that struggle to engage in the treatment [15, 29, 30].

YP reported learning more about their thinking styles and skills through the exercises, and some of them were able to apply this learning to their routine by being more flexible or by balancing out the big picture *vs.* detail approach. On a few occasions they used the skills learnt during CRT to face difficulties related to the AN symptoms. For example, they found it helpful practicing cognitive inhibition skills they learnt during CRT to block AN thoughts out during meals time. Developing further awareness of thinking styles and problem-solving strategies is an important step to be able to benefit from other psychological therapies (e.g. CBT). Also, it is possible that reflecting and applying therapy to thinking styles without focusing on AN thoughts made this type of work more acceptable [22].

Many YP also found that approaching personal challenges through exercises and homework less threatening. The playful and safe setting gave them the opportunity to challenge themselves gradually: initially during the exercise, then doing the homework and lastly in continuing to practice the new skill in their routine.

A few participants struggled to understand the goals of CRT. It seemed these negative thoughts about the intervention were possibly related to the lack of rationale provided prior to therapy; and also to the challenging nature of some of the activities. This emphasises the importance of providing further information to YP about the rationale and the real life application. Some of the developments in the CRT protocol (e.g. Manual developed by Maiden et al., [31] will improve individual protocol for YP by adding psychoeducation and additional exercises described in the manual.

Previous studies have analysed service users' feedback regarding CRT mainly in adult populations, and also in YP in a group setting. Similarities and differences between age groups are evident. Both YP and adults reported overall satisfaction with the intervention, noting it was valuable and acceptable. They appreciated learning new thinking styles and found the homework helpful. They both stressed the importance of an individualised approach, providing tasks adequate to ability. Furthermore they mentioned CRT was helpful in addressing perfectionist tendencies, fear of failure and rigidity of thinking styles. Also, both adults and YP described wanting more discussion about the relevance of the activities in relation to thinking styles and real life [21, 32].

There was less comparison of CRT to other therapies in YP letters which is different from adult CRT feedback [17], perhaps demonstrating a less reflective approach in a younger age group and less experience with different therapeutic approaches. Furthermore, YP talked about the importance of learning about thinking styles, whereas adults explored more the differences between working on the process of the thoughts and not on the content.

Metacognition is a complex process that implies the ability to reflect on our own thoughts and behaviours, which develops in the context of the improvement of the executive functions. It significantly develops with age during adolescence and reaches a plateau going into adulthood [33]. It is important to support YP to develop their metacognitive skills during CRT, possibly providing direct instructions regarding metacognition, an explanation on what this is and why certain strategies are important [34].

Within the letters YP expressed their gratitude to the therapists for their help, however they did not reflect any further on the therapeutic relationship. Also, YP liked that CRT was not focused on food and AN symptoms, while some of adult service users asked for exercises focused on eating [17].

Limitations and directions for future research

The sample included both children and adolescents who participated in CRT regardless of their stage of cognitive development and no distinction was made between the letters.

This qualitative study provides an account of CRT from the perspective of YP. It may be helpful in the future development of the intervention for younger population, particularly in relation to adapting the therapy to meet the ability of the YP and also in the development of information about the goals of CRT helping YP to understand more about its utility and applicability. In the future studies newly developed manual from the Maudsley group for YP should be also adopted [31].

Further research into the effectiveness will help to understand neuropsychological and treatment outcomes for YP with CRT. Furthermore, more in-depth qualitative research with a larger sample and longer term follow up will allow greater insight into YP engagement with the therapy and allow differentiation of outcomes and experiences for adolescents and children.

Compliance with ethical standards

Disclosure of potential conflicts of interest – All authors declare that they have no conflict of interest.

Ethical approval - For this study formal ethical approval is not required as the therapy, assessments and feedback letters from service users were a part of the standard treatment programme, and were conducted to inform the content of the Cognitive Remediation Therapy sessions.

Informed consent - Informed consent was obtained from all individual participants included in the study at the admission following the declaration of Helsinki.

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Table 1. Higher-order themes and Lower-order themes: frequencies and percentages

Higher-order themes	**YP N (%)**	**Frequencies**	**Lower-order themes**	**YP N (%)**	**Frequencies**
Engaging aspect of CRT	36 (51)	41	Games	22 (32)	27
			Learning about mind and thinking styles	7 (10)	7
			Distraction	4 (5.7)	4
			Homework	2 (2.8)	2
			Regular sessions	1 (1.4)	1
Identifying thinking skills	34 (48)	43	Thinking styles and problem solving	24 (34.2)	31
			Balance between an approach focused on big picture vs. details	5 (7.1)	5
			Awareness of personal struggles and skills	5 (7.1)	7

Relevance to real life situations	9 (12.8)	9	Ability to relate sessions to real life	5 (7.1)	5
			Being more flexible	1 (1.4)	1
			Use of pros and cons strategy in daily routine	1 (1.4)	1
			Schoolwork	1 (1.4)	1
			Importance of focusing on daily life challenges instead of food	1 (1.4)	1
Encountering personal challenges	14 (20)	14	Use of alternative thinking styles and techniques	5 (7.1)	5
			Games and tasks	4 (5.7)	4
			Dealing with changes in daily routine	5 (7.1)	5
Making sense of the rational of CRT	15 (21.4)	22	Not understanding the goal of CRT	5 (7.1)	5

			Not perceiving benefit of CRT	2 (2.8)	5
			Quality and difficulty of the games	4 (5.7)	7
			Negative feelings about CRT	4 (5.7)	5
Suggestions for further improvements	20 (28.5)	20	Length, frequency and setting of the session	7 (10)	7
			Variety, number and level of the games	5 (7.1)	5
			Explanatory information	3 (4.2)	3
			Use of homework books	3 (4.2)	3
			Difficulty of some assessment questions	1 (1.4)	1
			Personalised approach	1 (1.4)	1